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GOVERNOR'S COUNCIL FOR PEOPLE WITH DISABILITIES

ANNUAL CONFERENCE

"INVEST IN PEOPLE: SHARE IN THE PROFITS"

OPENING ASSEMBLY

INDIANA SECRETARY OF STATE TODD ROKITA and ANDREW J.

IMPARATO

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>> SUELLEN JACKSON-BONER: Now, I have another pleasure this morning to introduce a friend, a long time friend, actually, of the Council and a distinguished colleague, the Secretary of State of Indiana, Todd Rokita, who is speaking to us today about a subject we care very much about: The electoral process and the involvement of the disability community.

Many of you may recall the success of the Count Us In Project, the partnership between the Council and the Secretary of State, designed to increase the participation of Hoosiers with disabilities in the electoral process as voters and volunteers and to assist in the implementation of the Help America Vote Act. Let's give a warm welcome to our friend, Secretary of State, Todd Rokita.

[Applause.]

>> Todd Rokita: Thank you, Suellen. I really appreciate that introduction, it sounded better than when I wrote it.

[Laughter]

It is an honor to be with you this morning, you leaders. And I use that term very specifically and intentionally. Because each one of you are leaders. And my definition of leadership is that you each have spheres of influence. Spheres of influence in your families, in those that you work with, in

those that you serve and in those that serve you; and leadership is needed now in Indiana and across this nation perhaps more than ever.

And I know I'm at the risk of sounding a bit cliché, but it's true. And it's especially true in elections. So I'm going to talk to you for a few minutes today about what Indiana's been doing in regard to the election process and where we're going.

And then I know we have a keynote speaker in Andy that I'm very interested for you to hear, so I won't be long. But to the extent I could take one or two questions that you have, I'm happy to do that.

Before I go on, though, I do want to thank Duke Energy and Juli for your work. If an energy company -- if a big utility could have a fun, friendly and positive face, it's Juli, certainly at the State house. And I thank Duke Energy for all your involvement in the community, especially here.

Suellen, we've been friends for years. And I thank you for your leadership, also. And Mr. Chairman, Mr. Tilden, thank you for your leadership. And, Andy, I look forward to hearing some of your remarks, although I have already been summoned back to the State house. Something about redistricting here in the State of Indiana.

[Laughter]

So my apologies if I listen from the back of the room.

The Count Us In Project, I'm not sure if it was unique in the nation, but it's something that I think we can all together be very, very proud of. You know, shining the light on Indiana's 5500 polling places was something that took a lot of political courage. And I'm not talking about me. But at the county level, for the separately elected clerks, for the local bipartisan election boards, for the county commissioners whose legal duty is in this state to pick those polling places, it took a little bit of convincing, but not much, to say: Hey, before we go and spend hard-earned Taxpayer dollars on improving these polling places, let us first find out two things: Let us ask those of the community who need and want these improvements what we should focus on, and let's do a survey. Maybe not perfect. Maybe not completely scientific. But it would give us a great guide post, shed some good light on what we should be doing. And I guess there's a third one, number three: Let's have the disability community actually do the survey. Who better to tell us what is needed and where?

So in 2003 when we came into office on the heels of the Help America Vote Act, that's what we did. And we found out a lot of good information. And since then, we've spent \$600,000 in improving the physical attributes of the polling place. Or

we moved them to places that were accessible according to ADA standards.

And I'm here to announce that we have five -- gotten \$500,000 more in grant money from the Health and Human Services Department to do more work.

[Applause.]

I'm not sure if we're going to have time to do another survey, but here's the message to you leaders: Let your county clerks know what you think might be needed at a polling place you recently visited. Let your bipartisan board know and your county commissioners know. Those counties will be applying for that half a million dollars in money to our office. And when applying, they're going to have to detail how that money should be spent. So now's the time for leaders to act.

We also improved the voting machines, spending \$67 million, according to the Help America Vote Act. To make sure the machinery had accessories like headphones to read ballots via computer voice. As I go to the polling places, I'm not sure sometimes if those machines are being used or not or if we even know that they're there. So I want to make that announcement.

There's been some discussion about how perfect a voting machine is. And that debate rages on, especially in Washington, D.C.

As Chief Election Officer, here's my position on that: The voting machines that we use today, including the ones for use by the disability community, are light speed ahead of the levers, of the older machinery that they replaced. And the machinery that's on the horizon that's just on someone's mind right now that's in development that will take years to come to market, that go through rigorous testing and standards, those are going to be better than the ones we have today. That's the march of technology. And that march doesn't stop at the polling place.

But that's not a negative statement. And it's not a negative statement because of this: Elections are not carried out by machines. Elections are carried out by people. In those 5500 polling places, we have 30,000 poll workers, hopefully some of you working the polling place, conducting a legal and fair election. Not the government: People.

There's a distinction that's not always made, and it's sometimes hard to understand, but we don't want the government putting on our elections; we want us putting on our elections. We want us certifying and telling the government who we're going to send to it. And that's a distinction I hope is not lost. And it's certainly not the machines putting on the election.

The point being: If we have well-trained people with a good set of statutory law, which we do here in the State of

Indiana, so that a poll worker knows what to do if a machine breaks down or if a battery wasn't charged; and, number two, the law has a place so that we have an alternative, which we do in Indiana, for what to do when those things happen, then at the end of the day, we will still have a fair and accurate, if not perfect, election.

The media has somehow got us thinking that elections must be perfect. Well, I'm here to say that in the history of the world, there has yet to be a perfect election. Because elections are put on by people. And by Biblical definition of the word human, mistakes will be made. And again the key is: Is the training in place to work around those mistakes? Are the laws in place so that we have alternative ways to conduct a fair and accurate election? That's the key.

And as your Chief Election Officer, I'm here to say in the State of Indiana, that is the case. We have training that I think is second to none. We have very specific, common sense laws to encounter every issue. And now that I say that, there will be a new issue that we've never had come up in the next election. Maybe.

But with common sense, that Hoosier common sense that we're all born with, I know we can get through it. And with partners like you, the disability community, helping us, educating us to

use that tax dollar the wisest, to stretch it the farthest so that all people have accessibility to the polling place is what's absolutely needed. It's what I pledge to do in my next 13 and my last 13 months as your Indiana Secretary of State.

Suellen, thank you very much for having me. I really appreciate being here and I appreciate our partnership. Thank you.

[Applause.]

>> SUELLEN JACKSON-BONER: We appreciate the remarks from the Secretary of State. He's good to have as a friend.

I'd like to move on at this point in introducing our keynote speaker, Andrew Imparato. Andrew Imparato is the President and CEO of the American Association of People with Disabilities, AAPD, a national nonprofit, nonpartisan membership organization of people with disabilities, their family members and supporters.

Mr. Imparato oversees the organization's issue of political and economic empowerment of all people with disabilities through public policy, advocacy and programs fostering leadership development and mentoring and career exploration, voting and civic participation and member benefits.

Prior to joining AAPD in 1999, Mr. Imparato was General Counsel and Director of Policy for the National Council on

Disabilities, an independent federal agency advising the President and the Congress on public policy issues affecting people with disabilities.

He is frequently called upon to write and speak about disability issues because of his own personal experience with bipolar disorder.

Mr. Imparato has also been featured on many major news networks, including ABC, CNN, CBS, NPR and C-SPAN. And his op eds have appeared in the Washington Post, San Diego Union Tribune and other outlets.

Mr. Imparato was elected in 2003 to Executive Committee of the Leadership Conference on Civil Rights, the nation's largest and oldest coalition of organizations committed to promoting equal opportunity, equal justice and mutual respect.

Mr. Imparato also serves in formal advisory roles on corporate social responsibility, diversity, accessibility, disability marketing issues with Verizon, Time Warner, AT&T and America Online.

Mr. Imparato graduated with distinction from Stanford Law School and is a Summa Cum Laude of Yale College. Let's give a warm round of applause to welcome Andrew to the stage.

[Applause.]

>> ANDREW IMPARATO: Thank you, Suellen.

So, I got in late last night, which meant that I turned on the television and I saw what happened in the football game. So I want to pick up on Suellen's comment to put our excitement for the Colts and transfer it to disability rights. When I say "what do we want?" I want you to say "Disability Rights" as loud as you would do for the Colts. "When do we want it?" Now!

What do we want? Disability Rights!

When do we want it? Now.

When do we want it? Now.

Thank you.

I figured I better watch that game because it would affect the mood of my audience. I'm glad for the victory.

So I do want to thank Suellen Jackson-Boner for inviting me to be here with you, but also for her decades of leadership on our behalf. I'd like to just hear a round of applause for her.

[Applause.]

And I want to acknowledge Betty Williams, who is on the AAPD Board of Directors, who is in the audience. Betty is an advocate, is a national leader with self-advocates.

[Applause.]

Betty, thanks for being here.

So, just to fill in a little bit of my personal background, I think of myself as a second generation disability activist. I

graduated from law school in 1990, the year that the ADA was enacted into law. And I'm part of a generation of adults who have developed our careers in the wake of a law that protects our Civil Rights in the workplace.

So I really want to start by just acknowledging and thanking the pioneers who got us the ADA, many of them are here in the room, and who created a Civil Rights law that now has been around for 20 years and recognize that we do have a generation of professionals like me who have had more opportunities and who have been able to be open about our personal experience with disability, in part because we have a Civil Rights law that protects our right to equal opportunity in the workplace.

As was mentioned, my disability is bipolar disorder, manic depression. The way that it affects me is I go about six months of the year where I have a lot of energy, a lot of self-confidence, not a lot of patience, followed by six months where my energy goes down, my self confidence goes down, and I'm a lot easier to be around.

[Laughter]

And there are a lot of folks with that label who experience the symptoms in different ways. That's true for lots of disabilities. You can go through several cycles in one day.

But I benefited tremendously from being with the disability community, with the independent living movement, and the Disability Rights Movement in Massachusetts right as I was beginning my career and trying to figure out what this disability meant in terms of my opportunities as a lawyer.

And what I learned from the Civil Rights community in Massachusetts is that my disability, my personal experience was a source of credibility and connection to the issues that I was working on.

And I think as we come up to the 20th anniversary of the ADA, it's really worth thinking about what are we doing to help people have pride in their identity as people with disabilities? What are we doing to create a cross-disability consciousness so that people are seeing their connections with each other across the various labels that we have for our various disabilities?

And I believe there's an opportunity to do more in that area. And that it's when people are out, as people with disabilities in the workplace, that we then have the opportunity to change attitudes and raise consciousness.

But I still think 20 years after the ADA, we still have lots and lots of people with disabilities and chronic health conditions who aren't comfortable letting people know about it at work, who aren't comfortable self-identifying. And I think

that's holding us back as a movement.

There are lots of good reasons why people may not want to share that information, but we have to challenge that. And we have to, as a movement, encourage people to be out and open, not that it defines them, but that it's part of their life experience and it can help make them more effective in the workplace.

As was mentioned, I am based in D.C. and I've been in D.C. since 1993. I started out at the Protection and Advocacy Agency in Boston. I actually grew up in Los Angeles, so I wasn't sad to see the Patriots lose last night.

[Laughter]

But I started my career in Boston at the Disability Law Center and worked on SSI and Medicaid advocacy there, came to Washington in '93. And the last time we had a major health care reform effort going on, I went to work for Senator Tom Harkin from Iowa, who was the Chair at the time of the Senate Subcommittee on Disability Policy.

I went to work for the Equal Employment Opportunity Commission in '94 and then the National Council on Disability in '97 and I've been at APD since '99. So it will be 10 years for me with AAPD. I can't believe it's been that long.

I loved my job at the National Council on Disability. Part

of the reason why I was interested in joining AAPD is I felt like we were doing a lot of good work at NCD and other government agencies making recommendations to the President and the Congress, but we didn't have a big enough, organized constituency outside the government that was holding the government accountable. So I was attracted by the mission of AAPD, which was to organize the disability community, defined broadly, so that we have more power politically, socially and economically.

And it's been a real joy for me to be with AAPD for 10 years. We do have a great Board. Betty Williams, who is here in the audience, is a great example of the kind of leadership that we have on our Board. Our current Board Chair is Tony Coelho, who was the Democratic Whip in Congress who did the original draft of the ADA. He's a former Board Chair of the Epilepsy Foundation of America and has epilepsy himself. And he's just a phenomenal leader for our community and he's doing a great job as our Board Chair.

Our Immediate Past Board Chair is Cheryl Sensenbrenner, who is married to Jim Sensenbrenner from Wisconsin, former Chair of the House Judicial Committee. She is from one party and he is the other.

Tony was involved in founding the organization with Senator

Bob Dole.

And one of the things that we really try to do at AAPD is frame our issues so that we can move them forward no matter who is in power. Just having been in Washington for 16 years, most of the effective groups in Washington have found ways to work on a bipartisan basis to make things happen. I think that's one of our core strengths as a Civil Rights group for people with disabilities: We know how to work with both sides of the aisle. We know how to frame our issues in ways that people, different political affiliations can understand that our issues are their issues and that empowering people with disabilities to participate fully is good for the country regardless of one's political ideology.

I wanted to mention some of the advocacy issues that we're working on. And I'll talk more about this. And I'm also going to open it up for Q&A, because I want to have an opportunity to hear some of your questions and comments.

But one of the big issues we work on and I know Suellen knows this because she's a close colleague of Jim Dixon who leads this work for us, is around voting. So you just heard the Secretary of State talk about the Help America Vote Act. The Help America Vote Act is a major piece of Civil Rights legislation that AAPD worked very closely with the leadership

conference on Civil Rights to make happen in 2003. And that law required for the first time that every polling place in the country had the ability for people with any type of disability to vote privately and independently.

You would think that that right would have been established under the Americans with Disabilities Act, under the Equal Protection clause of the Constitution, but it helped us a lot to spell it out in the law and to create a funding stream to help states and localities modernize their election technologies. And as was mentioned by your Secretary of State, that's been a somewhat controversial thing because of the machines themselves have been controversial.

When we worked on the Help America Vote Act, there was no discussion of a paper trail. But once we got a law passed that required that electronic voting machines be in place in polling places, then people got worried about the need for a paper trail. And there's been a lot of fights around that. AAPD's position is that people with disabilities should be able to vote privately and independently. And if there's a way to do that and create a paper trail, we have no problem with that.

Unfortunately, it's taking a while for the election equipment industry to produce machines that provide equal access for people with disabilities and provide a paper trail. But as

your Secretary of State mentioned, I think it's only a matter of time before the technology catches up.

Speaking of technology, that's another issue that AAPD does a lot of work on. Jennifer Simpson, who is our sitting Director for Telecommunications and Technology Policy, has worked with a coalition that we helped to create called the Coalition of Organizations for Accessible Technology. And they have a piece of legislation now called the 21st Century Telecommunications and Video Accessibility Act, H. R. 3101, which would take the requirements of older laws, like Section 508 of the Rehabilitation Act and Section 255 of the Telecommunications Act and modernize them so that, for example, if you have a video that is captioned, you have content that's captioned on a video and you're showing it on a website, the captioning should carry through to the website.

There's things like that that have happened in the wake of the proliferation of the Internet that require our technology laws to be modernized. And that's something that we're working on with a lot of partners.

We also worked with a very broad coalition on the ADA Amendments Act to overturn Supreme Court decisions that had narrowed the scope of the protected class under the ADA. This was a bill that passed in the last Congress. The vote in the

House was 405-17. So that's an example of what you can accomplish when you have bipartisan approach and bipartisan leadership. That bill restores Civil Rights protections for people with epilepsy, diabetes, cancer, depression, a wide range of conditions where the courts were saying: If you were managing your condition well, then you did not have an impairment that substantially limits a major life activity, so we don't have to reach the issue of whether you were discriminated against because you're not in the protected class. And it was creating problems for people with a wide range of disabilities.

We had a case in the 11th Circuit where a person with an intellectual disability who was on Social Security wanted to bring his job coach with him to an interview. And the threshold issue in that case was whether he was disabled enough to have civil rights protections under the ADA. And the Court actually said they weren't sure whether thinking was a major life activity.

[Laughter]

So that's an example of how bad it was.

But the good news is that we passed the ADA Amendments Act. It was signed into law by President Bush. His father was there when he signed that law. And interestingly, that was the only

bill that the most recent President Bush signed where his father was there for the signing ceremony. It happened towards the end of his second term. But now we're in the process of implementing that.

I hope you all have seen the proposed rule from the EEOC. It's in a comment period right now. And the comments are due on November 23rd. We feel good about the proposed rule. We feel like it's consistent with the statute. And it's going to simplify the process under which people with disabilities demonstrate that they're in the protected class.

But I'm confident they're going to get comments from some of the employer community who are going to express concern that these regs are too broad. So I think it's going to be very important that they hear from folks in the disability community what you like, what you don't like. And I encourage folks to comment. You can get the rule at the EEOC website, which is just EEOC.gov. But, again, the deadline for the comments is November 23rd.

Finally, I just wanted to mention a new coalition that AAPD is working with to do our advocacy work. This is something that we created during the transition to the new Administration. We decided there would be value in having a coalition of organizations that are disability consumer organizations, that

are disability-led and that have identifiable grassroots constituencies around the country.

So we created a group that we're calling the Justice for All Action Network, which has 13 national disability organizations working together. We actually talk once a week. And we've developed a joint legislative strategy that we're all supporting that reflects the top priorities of the different groups in the coalition. Included in the coalition are Self-advocates Becoming Empowered, ADAPT, the National Council on Independent Living, the Autistic Self-advocacy Network, the National Federation of the Blind, the American Council of the Blind, the National Association of the Deaf, the United Spinal Association, the National Coalition of Mental Health Consumer Survivor Organizations -- and I apologize, to the interpreters, I'm going fast -- Not Dead Yet, Hearing Loss Association of America and AAPD.

So you would think that these groups nationally would come together. But actually before we created this, a lot of the leaders of these groups didn't know each other, and it's been fun to watch how the cross-disability collaboration is happening.

One of the themes that resonates for a lot of these groups is the idea of "nothing about us without us." If you're going

to make policy affecting people with disabilities, make sure --

[Applause.]

-- make sure that people with disabilities aren't just involved, but are in the driver's seat. And that's really why we created this coalition. We're collaborating with bigger coalitions that include major service provider groups, parent groups, professional groups.

But we felt like this first person perspective was important. It wasn't getting heard enough. Particularly with a new Administration, we wanted to make sure that the President and the leaders coming into the administration understood the importance of talking directly to people with disabilities and disability-led organizations.

So that's been a fun effort, and we're going to be announcing our 12-point agenda next month on December 3rd, which is International Day of Disabled People. And there's usually activities around that in Washington.

I mentioned that I'm a second generation disability activist. And I wanted to just share -- I think one of our responsibilities is to educate the generations that come behind us about our community, what our issues are, independent living philosophy, disability rights philosophy.

So I started at home with my now 16-year-old. But when he

was three, he was in preschool and my wife and I were invited to come and speak at the preschool about what we do for a living. It was called Community Help First. The idea is what do you do and how does it help the community?

So my wife is a history professor and she came in -- college-level history professor -- she came in and brought in kind of age-appropriate historical artifacts for the three year olds and got them excited about history. And the preschool teachers were kind of wowed that she could do it.

So the pressure was on when I had to talk about what I do for a living. At the time I was at the Equal Employment Opportunity Commission. So I wanted to get across that I work for the government, that we did Civil Rights work in the workplace and that my specialty was disability within Civil Rights.

And I kind of intuited that maybe the hardest thing for the three year olds was going to be the concept of disability. So I was practicing at home with my three year old. And I said, "Aggie, do you know what a disability is?" He said "Yeah." I said, "What is it?" And he said "I don't know."

[Laughter]

And I said, "Well, you know, like somebody who uses a wheelchair. Who do you know who uses a wheelchair?" He said,

"Chris Griffin." And he knew Chris because she worked with me at the Commission. And she gave him a lot of presents. So she was kind of high on the radar screen.

"Or somebody who is blind who uses a white cane. Who do you know who is blind?" And she said "Chris Kaczynski." Again he knew Chris because Chris worked with me at the Commission and he commuted with me from Baltimore and sometimes we'd give him a ride home from the train station.

"Sometimes people have a disability but you can't tell from looking at them that they have a disability. And some people call that a hidden disability." I said, "Can you give me an example of a hidden disability?" And without missing a beat, he said, "Like being a lawyer?"

[Laughter]

[Applause.]

Sometimes the true stories are better than anything you can make up.

Now, it so happened at that point in his life, the people with disabilities that he knew were also lawyers. So, some people might see it as a sign of progress and some might not. But it is a true story.

I wanted to just share one other story before I talk about some of what's going on in Washington. And this goes to this

kind of hidden disability category.

When I was finishing up my fellowship in Boston, I was applying for jobs around the country. And one of the jobs that I applied for was a staff attorney at a national organization that did advocacy for people with primarily with mental health disabilities. So I self-identified in my cover letter as a mental health consumer. And the person who was doing the screening for the -- to figure out who to interview, he talked to one of my references about me being a mental health consumer and basically wanted to make sure I was okay. And the person he talked to was the person who funded the fellowship. And she knew about my disability because I had told her about it. She said "well, you really should talk to him about it."

So I came to town to interview with Senator Harkin's office. And while I was in town, I asked them if they wanted to interview me. So they agreed to interview me. And there were two lawyers in the room. Keep in mind, both of these attorneys were national experts on the rights of people with mental health disabilities. And we went through the entire interview and they never brought up me being a mental health consumer.

So at the end of the interview, I said, "I know you talked to one of my references and I just want to take this opportunity to answer any questions you might have." The lawyer who did

that didn't say anything. And he looked kind of nervous. The other lawyer who looked even more nervous said, "Well, is there anything you want to tell us"? Which was about the only legal thing she could say at that point because this was pretty off here. So I talked to my disability to some degree.

Her initial reaction was "oh come on, Andy. We all see a therapist. Why is that relevant?" And I took that as kind of a check that they're used to working with people with real psychiatric disabilities, and my condition was not that significant. So why was I kind of adopting that status?

So I talked a little bit more about my condition, some of the uglier aspects of it, because I took it as a challenge to whether it was real.

Then she, like, kind of a light bulb went off and she said "oh, you're bipolar" and she described a staff person they had had who was bipolar who was inappropriate at staff meetings.

I ended up working for Senator Harkin, which was probably a better thing for me, anyway.

I like to tell that story because I don't think that experience is that uncommon for people who have nonapparent or nonvisible disabilities. There's a tendency for people to think that either it's not significant enough to matter, so kind of get over it, it doesn't count, you're just trying to use it

inappropriately, or it's so significant that you're not qualified or desirable for the position that you're trying to apply for.

And I think that's one of our challenges again as we come up to 20 years of the ADA. How do we create that broad area where, yes, it's real and, yes, you're qualified? And I think that's one of the messages of the ADA. And that's one of the problems we have with the courts around -- they were knocking out people with depression and cancer, a lot of people with nonapparent disabilities, a lot of people with chronic health conditions. It was hard for the courts to understand that you could manage that condition well and still experience egregious discrimination in the workplace. And the point of the ADA is there are lots and lots of people with lots and lots of skills who experience discrimination and aren't able to show what they can do.

So I think that's one of our challenges again coming up to the anniversary. How do we remind society that there is this broad category of people who are qualified and disabled?

So I want to go to your theme for your conference, "Invest in People and Share in the Profits." Sounds very capitalist.

[Laughter]

Which I don't have a problem with.

Sometimes I describe my own politics as I'm a venture populist. In the sense that I like to leverage industry to try to make the situation better for the average person. I think it's possible to do. Some would argue that it's not. But I do think it's possible.

I think your theme of investing in people is exactly the right theme as we come up to the 20th anniversary of the ADA and the 35th anniversary of the Individuals with Disabilities Education Act. IDEA is a law that's about investing in children so that they can learn to their maximum potential. And that's the right frame for disability policy.

Now, I would argue that that has not been implemented very effectively and it hasn't been enforced very effectively. But the idea of making the upfront investments is the right idea. Vocational rehabilitation again is about investing in people, helping them build their human capital. There are a lot of problems with how it gets implemented on the ground, but the frame is the right frame.

But those programs are relatively modest programs compared to the four big programs that serve people with disabilities. What are the four largest priorities from a budget standpoint that serve people with disabilities? Social Security Disability Insurance, Supplemental Security Income, Medicaid and Medicare.

Those four programs, according to the Government Accountability Office, about three years ago we were spending \$300 billion a year on those four programs. Vocational Rehabilitation we spent about 2.6 billion. So there's a pretty big difference.

Those four programs, I would argue, need to be modernized so that they have an investment orientation. Those programs, to a large degree, are about maintaining people in poverty. That's what they were created to do. And when people try to earn money, try to save money, try to participate fully in the lives of their communities, they often get punished by antiquated rules that were designed at a time when we had lower expectations.

[Applause.]

So I had the chance recently to serve as a Democratic Senate appointee to the Work Advisory Panel. And the leader of that panel, Bertha De la Rosa Puente, had the courage to create a committee called the Transformation Committee. In that committee, which she asked me to Chair, we looked at these programs and said how can we transform them so that they're more consistent with the goals of the ADA?

And I want you to know this was very controversial stuff that we were doing. We had a letter from the Chair of the House Ways and Means Committee and the two subcommittees that oversee

Social Security and SSI that was sent to the entire panel saying that they were not interested in transformations.

We had the Commissioner of Social Security call our chairperson into his office and scream at her that what we were doing was illegal. Okay. That was outside the scope of our charge as a bipartisan advisory panel.

So somehow we were striking a nerve when we talked about transforming these programs. And I think that's one of our challenges that we face, again, as we tell you about investing in people. Investing in people requires taking some risks. And oftentimes when you try to have a conversation about how to change the income support programs and the health programs, the first thing you hear is: These programs are working for most of the people who are on them. And whatever you do, make sure you do no harm. And then that translates into: Don't change too many things with these programs or we could end up with something worse. We heard that over and over again from the professional advocates. But when we went out and talked to beneficiaries, people who were on the programs, they were ready for big changes.

I know very few people who like being required to swear to the government that they're unable to work in order to get health care, in order to get income support.

[Applause.]

And I think it's particularly problematic when we require 18-year-olds who have not even tried to work yet, one of the first thing we ask them to do is to go down to Social Security and swear that they can't work. That's immoral. I believe that's immoral. It's bad policy. There's no reason it has to be.

We can have a definition of eligibility that talks about barriers to employment and then we can identify those barriers and develop strategies to address those barriers. That's modern disability policy. But that's not the way our large entitlement programs operate. The definition of eligibility for Social Security dates back to 1956. So that's over 50 years ago.

Our thinking about the capacity of people with a wide range of disabilities to work, to contribute to the economy has evolved during those 50 years; but where we're spending our money has evolved very slowly. We have the Ticket to Work program. We have work incentives in Social Security. But we haven't changed what you have to say in order to get in the door of Social Security.

And people wonder why aren't more people using a ticket? Well, if you have to spend two years convincing the government that you can't work and then you get a ticket in the mail saying

"here, use this to go get a job", most people understand that this is the last test. They're actually checking to see if I'm really disabled. It's a cognitive disconnect to ask somebody to prove that they can't work and then to use their ticket to go out and get a job. So I would argue that that's one of our big challenges when we talk about investment.

And I just wanted to share one of the ideas that came out of the Ticket panel, which I think is worth kind of discussing at the state level and there may be ways that you all could demonstrate in Indiana how to do a program like this, getting waivers from the Federal Government.

We suggested creating a program called Transition to Economics Self-Sufficiency, or TESS, that would serve people between the ages of 14 and 30. And we said for this program, nobody should have to say that they can't work. It should be about identifying barriers and then developing strategies to address them.

We suggested doubling the budget for Vocational Rehabilitation, but spending all the new dollars on this target population on the theory that if we make an investment up front for young people as they're transitioning from school, or as they get young adult-onset disabilities like bipolar disorders is one that happens as somebody is becoming a young adult, let's

make the upfront investment so that we can see the return on that investment over time.

Now, you may see that if you double the budget for VR at the national level, that's \$2.6 billion. Where will you get that money? Let's keep in mind if you do nothing, GAO three years ago said we're spending \$300 billion on those programs, but that they were all growing at a rate that by 2020, if we did nothing, it would be \$1 trillion. That was the growth rate three years ago. In this economy, the growth rate has gone up. So we may hit a trillion dollars by 2018.

So if we do nothing, we're spending 700 billion new dollars on this population, which at some point becomes unsustainable. So I think we do have to, as disability leaders, we have to come forward at the state level, at the national level, at the local level and say we could spend this money in a better way. We should be investing in people, build their human capital, encourage them to develop their assets, encourage them to get into independent housing, teach them independent living skills, invest in supported employment, invest in accessible transportation and housing so that we actually have an infrastructure in this country -- [technical difficulties.] That to me would be be part of an investment agenda.

I'm going to touch briefly on some opportunities in the

wake of healthcare reform at the national level.

I was asked not to talk about health care reform because Liz Savage is coming tomorrow, and that's her topic for tomorrow. So let's assume we have some kind of healthcare reform as of early next year. I know that's not a safe assumption, but I'm confident that Liz will give you all good pointers to help us get that ball over the goal line, to go back to the Colts.

[Laughter]

So here are some opportunities in the wake of healthcare reform. I'm just going to mention five areas: Employment; entitlement reform, which we already talked about; Civil Rights enforcement, education reform and the Federal bench or Federal judiciary.

So, in terms of employment, this Administration is very interested in using the Federal government to demonstrate how to be a model employer for people with disabilities. The Federal Government used to be a leader at employing people with disabilities. But it actually started -- the decline started in the Clinton Administration. We've actually seen a decrease in employment of people with significant disabilities in the Federal Government by a rate 7-1/2 times the general reduction in the Federal workforce between 1994 and 2003. And since 2003,

the number has continued to go down.

So the way that works in the Federal Government, there aren't that many employers where we actually have statistics like this. But in the Federal Government, when you are a federal employee, you're given a one-page form to fill out when you start work where you have the opportunity to self-identify as an employer with a disability. So we have statistics. And they created a group of what they called targeted disabilities, which tend to be the more significant disabilities, that they track year-to-year.

And, again, right now in the Federal Government, based on the most recent statistics we have, guess what percentage of federal workers -- keep in mind the Federal Government is the largest employer in the country -- guess what percentage of federal workers are people with targeted disabilities, which include deaf people, blind people, people with psychiatric disabilities, intellectual disabilities, people with mobility impairments? Guess what percentage are people with targeted disabilities as of the most recent statistic? 2%? 2% would be nice. It's actually .88%. It's less than 1%. And that number has gone down every year since 1993.

So there's a serious problem in the Federal workforce. I think one of our opportunities with the Obama Administration is

to get serious about changing that curve. The person that's been raising this issue loudly in Washington is Christine Griffin, who is a disabled woman who was appointed by President Bush as a Democratic Commissioner to the U.S. Equal Employment Opportunity Commission. Chris has been appointed by Obama to be the Director of the Office of Personnel Management. The Office of Personnel Management is basically the HR agency for the whole Federal Government. The person who is leading it is a guy named John Barry. And John and Chris together are really interested in really pushing the Federal Government to set goals. Start with 2%, hit that goal, then keep working your way up. And make sure that by the end of this Administration, we have turned a corner and the Federal Government is actually hiring people with disabilities into the federal workforce at all levels.

That, I think, is a real opportunity in terms of partnership. There are lots of federal jobs in Indiana. Everybody in this room could be working with the Federal Executive Council that represents Federal agencies that have a presence here and make sure that they have strategies that involve partnerships with the disability community. This is going to be new for some of these Federal agencies because they don't have a history of doing a lot of aggressive outreach to find talented, qualified people with disabilities. But there's

an opportunity with this Administration. I encourage you to take advantage of it.

And tell Chris Griffin and others what it will take to work outside Washington. Because most of the jobs are not in Washington; they're around the country. We have to make sure the strategies are working on the ground.

Another opportunity related to employment is around Federal contractors. Federal contractors represent a huge part of the workforce. And there's a provision in the Rehabilitation Act that has never been enforced that requires Federal contractors to do Affirmative Action -- affirmative outreach to find people with disabilities. So we now have the person at the head of the compliance program that oversees that program named Patricia Shiu, who is a Civil Rights lawyer who came from the Employment Law Center in San Francisco where she was representing clients with disabilities, and she is working hard to enforce those provisions.

Let me just give you an idea of how this works when OFCCP does an audit. Typically OFCCP will go into a large Federal, like Lockheed Martin. They'll go in and say, "I need to see your numbers of women and what positions they are in your workforce. I need to see your numbers for racial and ethnic minorities and where they are in the workforce." And they get

very specific. And then if there's a problem, the audit identifies goals and targets to address.

When they're talking about people with disabilities or veterans, which are two other groups that they have responsibilities for, they don't ask for numbers. They just say. "What's your strategy for reaching out to people with disabilities?" If they say, "Oh, we have a relationship with our state VR agency," that's the end of the discussion. So if there's no outcomes from that relationship, if they haven't actually hired people, there's no accountability.

So I think we're going to see, under Patricia Shiu's leadership and ultimately under Secretary Solis as the Secretary of Labor, we're going to see much more attention to federal contractors to make sure that they're actually hiring people with disabilities.

And I know in this economy, there aren't a lot of people hiring. But believe it or not, particularly with the stimulus, Federal contractors are one of the groups that are hiring. There is an opportunity, particularly as the economy turns around, there will be more of an opportunity to really push this issue.

The last thing that's happened recently around employment that I just want to mention is Senator Harkin, my old boss, is

now the Chair of the Senate Committee on Health Education, Labor and Pensions. When Senator Kennedy died, Senator Harkin took over the chairmanship of that Committee. His number one priority moving into the next session of Congress is going to be employment. So you should expect some kind of legislation coming from him that really prioritizes employment of people with disabilities.

We have to reauthorize the Vocational Rehabilitation Act. I wouldn't be surprised to see him work to build a larger employment bill that includes a reauthorization of the VR legislation. So that's another opportunity where I think folks in Indiana could be coming to Senator Harkin's office with ideas and coming to your Senators with ideas of what you want to see that would actually have an impact around employment.

Second area of opportunity is the entitlement reform. I think the number one domestic policy priority of the Obama Administration after healthcare reform is going to be entitlement reform. And when they start that process, they're going to be talking about things like the solvency of the Medicare program, the solvency of the Social Security trust fund.

And it's our job to help them understand that the kinds of transformation and investment policies that I talked about

earlier should be part of a discussion about entitlement reform. Because, again, the growth rate in all of these programs affects solvency. It affects whether we're getting any kind of a return on investment on the money that we're spending. So I feel that we have an opportunity.

When Obama was a candidate for President, he called for a bipartisan commission to look at Social Security and work incentives and employment. So we've been working on a draft Executive Order that would implement that. But, again, I think there's an opportunity to make that discussion happen as part of a bigger discussion around entitlement reform.

The other thing that needs to happen as part of that is a real discussion about how to modernize Medicaid and Medicare so that we do not continue anachronistic rules in those programs that hold people with disabilities back.

Candidate Obama called for eliminating the institutional bias in the Medicaid program. We've had a lot of politicians calling for getting rid of rules in Medicare, like home bound requirements that punish people for leaving their house or make it impossible for them to get technology or services that they need to leave their house. These are all things that could be changed as part of a modernizing Medicaid and Medicare.

And I do want to mention the person who Obama appointed to

be the head of Medicaid is a woman named Cindy Mann, who was one of the leading advocates for low income children and families outside the government. So she's not afraid to view Medicaid as a program that's about empowering people and about providing opportunities. That's the framework she comes from. I think having her as the head of Medicaid is a welcome change that could lead to some positive change around entitlement reform.

But again I want to emphasize: Look at Welfare reform. You could argue about whether Welfare reform worked well for people with disabilities. But the way that we built the consensus nationally to do Welfare reform was by innovating at the state level. States like Wisconsin led the way, showed the country how to do it. And then we did it at the national level.

So if you're interested in these kinds of reforms, I would be looking to implement them at the state level, work with your state legislature and your leadership here to develop new models and then have the Feds give you the freedom to experiment with new models.

Just to give you an example, the Vocational Rehabilitation Commissioner of Wisconsin, Michelle Dwyer had a program "Making Work Pay" where they are trying to get Federal agencies to give them more waivers instead of just having a Medicaid buy-in, people with disabilities could buy into all the supports that

they have, including housing and other types of supports so that they could keep what they have when they go to work and it would be kind of a Medicaid buy-in. That's the kind of experimentation that I think is interesting that's probably going to happen first at the state level before we're able to get it done at the national level.

Civil Rights enforcement. I had the opportunity to go to the installation ceremony for Tom Perez on Friday. Tom is the incoming Assistant Attorney General for Civil Rights. He is a very strong disability advocate. And one of the things that he said -- he gave a great speech at his installation ceremony where he was answering the question: Why do we still need a Civil Rights division? And one of the things that he said that I thought was powerful, he said that when people with disabilities are segregated in institutions and other settings, that's just as wrong and just as illegal as segregating children on the basis of race.

He drew the connection between that kind of segregation and racial segregation, and he called for the Justice Department to show the same kind of leadership to address warehousing people with disabilities in institutions that the Justice Department showed historically to address schools' desegregation.

To me, that's the kind of leadership that we need at the

Department of Justice. They've already intervened in an Olmstead case in New York. And I think you should expect to see more of that.

If there are problems here in Indiana around Medicaid cuts where the state is moving backwards -- and I know that's been true in a lot of states around access to services in the community -- that raises Olmstead issues. It raises Civil Rights issues under the ADA's integration mandate. And I would encourage you to reach out to the Justice Department. The person to reach out to is Deputy Assistant Attorney General for Civil Rights, his name is Sam Bagenstos. And he is a disability rights lawyer. He's argued a number of ADA cases in front of the Supreme Court. But Sam was the one who got them involved in New York.

And they're looking for other states where they can send a message that it's not okay to cut services in the community in the name of trying to balance the budget, particularly if the end result of that is you have more services in an institution, more services being provided in institutions than you had before the cuts.

I think we're going to see leadership on Civil Rights in the area of technology accessibility. We have a President that is excited about technology. And he understands that technology

has to be accessible for people with disabilities in order for it to create the transformational opportunities that he wants it to create for everybody.

Tom Perez and Eric Holder, the Attorney General, have both met with the disability community and said that technology accessibility is going to be one of their priorities.

This is an area where the courts have been mixed. Some courts have said that the ADA doesn't apply to the Internet because the Internet is not a place. Other courts have said most business happens over the Internet these days. If the Internet is not accessible, then we're excluding people with disabilities from the Internet.

Again, I think we've got a Justice Department who will push that envelope more under this Administration. And that's going to be a welcome change.

We're also going to see leadership on accessible voting. I understand that you all had a ruling recently in the state that said for early voting, as long as people with disabilities have some way to vote early, all of the ways to vote don't need to be accessible.

Well, from my experience and my expectation, that's a good issue to raise with the Justice Department, because this is a new thing. Early voting is getting more and more popular. And

if we start making people with disabilities go one direction and everybody else has all these other convenient ways to vote early, it seems to miss the point of the Help America Vote Act. The point of the Help America Vote Act is that people with disabilities have a right to vote just like everybody else.

[Applause.]

If we're creating opportunities to make it easier for people to vote, which is a good thing, then let's make sure it's easier for people with disabilities to vote, as well.

Lastly, and this is an issue that I think Indiana can also be a leader on, when we passed the ADA in 1990, the EEOC and the Justice Department contracted with the Disability Rights Education Defense Fund, and they sent them around the country to train people who could then go out and do more trainings, so people would know their rights under the ADA. So, Ellen, I'm betting that you went to one of those trainings.

We need to have that kind of training happening on a regular basis. When I was at the National Council on Disability, we looked at Federal enforcement of the ADA , IDEA, air carrier accessibility, Fair Housing Act, lots of different laws. And we found over and over again that it wasn't the government that was enforcing these laws on the ground; it was people with disabilities and it was parents of children with

disabilities who were enforcing these laws on the ground.

So, if you don't know your rights as a person with a disability or you don't know your rights as a family member, it's much less likely that those rights are going to be respected and then you're going to actually get equal access and equal opportunity.

So one of the things we raised when we met with Tom Perez is we have a bunch of new laws that were passed in the last Congress. We have the ADA Amendments Act, and again the regulations are pending right now. We have the Genetic Information Nondiscrimination Act, which prohibits discrimination on the base of genetic information. And we have the Mental Health Parity legislation. So those are three brand new federal laws that create new rights for people with disabilities, or in the case of ADA Amendments, restore rights for people with disabilities. We should be out there with training so that people know their rights.

And I think, again, Indiana could be promoting this idea with your Congressional delegation and say: We're coming up on this major anniversary. We have all these new laws. Make sure that there's a budget for the enforcement agencies to be out there doing training, either themselves or contracted out to a group like DREDF like they did last time. But make sure it's a

regular thing and that we can get the training in multiple formats and multiple languages so that people with disabilities know their rights. And I think there's an opportunity around that.

Fourth area I want to mention is education reform. The stimulus legislation had a huge federal increase in IDEA money. Huge. It's probably one of the biggest things that was in the stimulus legislation. It's our job to tell the local education agencies and the state education agencies how to use that money to actually improve outcomes for children with disabilities under IDEA. They have all this new federal dollars. Where's the accountability for the new federal dollars?

We have a brand new Assistant Secretary for Special Education and Rehabilitative Services. She just started last week. Her name is Alexis Posny. She was in the state of Kansas. And before that, her specialty is special education. She is going to be focused on trying to make sure that those new federal dollars are actually getting spent in a way that improve outcomes.

The Secretary of Education has this Race to the Top initiative right now. I don't know if people are familiar with it, but it's creating incentives for schools to compete with each other to kind of show how great they are. We need to make

sure that one of the things they're competing around is showing how great they are in education opportunities and achievement for students with disabilities. And if that's not implemented properly, it can actually produce a perverse incentive where the schools that have a smaller percentage of students with disabilities are somehow in a better competitive advantage.

So, again, I think that's an opportunity for us around education reform, make sure that the Race to the Top includes children with disabilities in a way that makes sense and that schools are getting rewarded for actually implementing best practices in education for disabled students.

You're also going to see some legislation -- this is being led by Congressman George Miller, who is the Chair of the House Education and Labor Committee, to address the use of seclusion and restraints and adversives in the schools against children with disabilities.

The Government Accountability Office recently documented -- and then the ACLU did their own report -- documented that students with disabilities are experiencing kind of grotesque discrimination in the schools where schools are buying little isolation chambers and sending students with disabilities to them. There's a whole industry that has grown up to sell this kind of stuff to schools. And it raises huge Civil Rights

concerns.

Now, I think you could argue we already have tools to address that under ADA, 504 and IDEA, but Congressman Miller is working on some bipartisan legislation to make it crystal clear that there are better ways to manage behavior in the classroom than putting a child with a disability into solitary confinement, which is what some schools are doing right now.

[CHEERS AND APPLAUSE]

So the final area I wanted to mention is a post healthcare opportunity is the federal judiciary. This is something that I care a lot about because I'm very angry at the Supreme Court and where the Supreme Court has been in disability. I would argue to you that we're still waiting for a Brown versus Board of Education decision that really recognizes the constitutional protections for people with disabilities.

This Supreme Court, particularly under the leadership of Chief Justice Rehnquist, had opportunities to lead in the disability area and failed miserably. The best example was the Garrett case, Garrett versus University of Alabama. This involved a nurse with breast cancer who was out for chemotherapy. And when she went back to work for the state hospital, she was a state employee, they demoted her because they were worried that she wouldn't be an effective manager

after her chemotherapy.

So she challenged that under the ADA. And the state of Alabama argued successfully to the Supreme Court that Congress did not have the authority to give her the ability to sue the State of Alabama for money damages under the Constitution. And it was basically one of these states' rights decisions, which they call "Federalism." But it's really just a new version of states' rights.

And there were two issues in that case. And this is the way the Rehnquist court looked at Congressional authority. The first issue was: Was there a history of unconstitutional discrimination against people with disabilities in employment by states that justified Congressional action? And if there was such a history, was the ADA a proportional response?

Rehnquist actually wrote the majority opinion. And he said that there was no history of unconstitutional discrimination because the ADA requires employers to provide accommodations, and that goes beyond what's required by the Constitution.

And what he was basically saying is that it's rational for employers not to provide accommodationless. So because the ADA goes beyond that, we don't see a history of unconstitutional discrimination.

It was totally bizarre, but that's the analysis. It was a

5-4 decision. And that's what we're stuck with. That's not a simple thing to overturn. We can't just pass a law that documents a history of unconstitutional discrimination, because we did. It's called the ADA.

And if you look at the dissent in this case, written by Justice Briar, he attached 60 pages of the Congressional Record documenting the history of discrimination. He went back to Justin Dart's Congressional taskforce and all the documentation that happened. And the Rehnquist court said that's not good enough.

So one of the things that we're doing in AAPD is we're trying to pay attention to who gets appointed to the Federal bench. The Clinton Administration was interested in having a more diverse federal bench, but they weren't really looking at disabilities and diversity category. We're trying to make sure under the Obama Administration that we actually get people with disabilities appointed to federal judgeships.

And we were very excited about Sonya. She was the one that had childhood onset diabetes. When the President introduced her to the country, he talked about her experience as a child and how she wanted to be Nancy Drew when she grew up and people told her she couldn't because of her diabetes. If you look at her record on the bench, she had a very strong record on disability

rights. So I'm hoping that Justice Sotomayor will write some good decisions, to say yes, Congress has the authority to protect our Civil Rights, yes, there has been a history of unconstitutional discrimination not unlike the discrimination against other protected classes, and, yes, Congress is in a better position to determine the appropriate remedy for that than the lifetime appointees to the Supreme Court.

So I just encourage us to be thinking about that. There are District Court vacancies here in Indiana. There are Appellate Court vacancies that affect Indiana. And you all could be working to identify people in the Bar, both people with disabilities and people who have good track records on these issues, could be family members, too, who would be good candidates for those vacancies.

As a community, we don't have a lot of history on focusing on judicial nominations, but I feel like that's part of our problem. We're not paying enough attention to who's getting appointed to these judgeships and then we get these bad decisions and we wonder why.

So just briefly, I've laid out some of the opportunities. What are some ways that people in this room can engage on these and other issues?

First, if any of these issues is something that you're

interested in working on, please use it as an organizing tool to build your lists and then work those lists to make sure that your folks are registered to vote and make sure that they're voting.

One of the mistakes that we make sometimes in the disability community is we focus on advocacy without doing the organizing. And to me, the advocacy is only as valuable as the organizing around it, because whatever fight you're having, it could be a state-level fight around Medicaid cuts or whatever, whatever fight you're having, make sure that you're stronger at the end of that fight than you were at the beginning. And the way to do that is by using the fight to organize people. And now we have easy technology tools to do that.

We created an AAPD cause on Facebook in August. And as of this weekend, we had 5,000 people in that cause.

[Applause.]

There's no reason you can't do that at the state level and local.

I also just encourage you to recognize that the national advocacy is a piece of what you all can do around your investment agenda. If you want to stay abreast of what's happening nationally, if you go to our website, AAPD.com, you can sign up for our free listserve, which is called Justice for

All. That is a great way for you to stay in touch with what's happening nationally around healthcare reform and other issues at the national level.

We also, as I mentioned, have this cause on Facebook, so I encourage folks to join it.

I just noticed we have another AAPD Board member in this audience, Rahnee K. Patrick, if you want to raise your hand, Rodney?

[Applause.]

Rahnee is a great advocate from Chicago. She works salinity access living. Metropolitan Chicago. She's also active with ADAPT. And she's one of our emerging leaders who we recognize for the 10,000 cash award called the Paul Hearne leadership award. But like I say, I have a great Board and two of my great Board members here are here in the audience.

Another opportunity I want to mention is leverage the ADA anniversary to deliver a message to the media and to come together as a community to chart a course for your future. We are going to have the attention of the media at the local level, the state level and the national level around that anniversary. It's a big anniversary. Use it to talk about what's working and what's not working at the local level and the state level. And use it to bring people together.

The National Council on Disability is having a summit around the anniversary. But that's only going to involve 300 people in Washington. You all should have your own summit here in Indianapolis where you could have a regional summit where you can talk about what's working and what's not working and what can we do together collectively to make sure that we're making progress consistent with the goals of the ADA.

And then, lastly, and I know this is a sophisticated audience so you know this, but get to know your United States Senators and your Congressmen. There aren't that many from the great state of Indiana, but they're all important. They all have power. They all can make things happen at a national level. Your two senators are going to be very important on healthcare reform, and that's just one example. There are lots and lots of issues where we have a closely divided Senate. And we have 60 Democrats, but it's not easy to get all 60 of them to vote for anything. And most things require more than that.

So you all need to help your Senators and your House members know what they're doing is going to affect people back in Indiana, back in Indianapolis. And you are going to have more of an effect on them than a paid lobbyist in Washington, D.C. is going to have.

So if you haven't taken the time to show up at a town hall

meeting or show up wherever they are, whether they're in district or in the state, take the time to do that and make yourself known. Make sure they know who you are and that you're interested in working with them to make sure that policy is going to work for people with disabilities on the ground.

So I do want to open it up for a little bit of Q&A. I'm going to close with a quote from Martin Luther King. Dr. King said that "human progress is neither automatic nor inevitable. That every step toward the goal of justice requires sacrifice, suffering and struggle, the tireless exertions and passionate concern of dedicated individuals."

Friends, you are those dedicated individuals. And it is my honor to be with you this morning. Thank you very much.

[Applause.]

I'm happy to take questions or comments and I'll repeat them from the microphone if anybody can't hear.

>> Of the stimulus money that came back to the states, of course Indiana in this case, is some of that available to relieve the Medicaid situation? And if so, how can we, as lay people, find out? Our son is developmentally disabled, but the state officials are telling us well Medicaid money is drying up. We can't find money. So your budget for our son has to be cut.

>> ANDREW IMPARATO: So the question relates to the stimulus

and whether some of the stimulus money that Congress passed that flowed down to Indiana is available to basically help fight or alleviate cuts that are being proposed at the state level.

The answer is yes, but it wasn't enough money. So I actually think our stronger argument on that front is going to be an ADA argument, trying to get the Justice Department and the Medicaid Director out of Washington to send a message to the State of Indiana and other states that when you're doing cuts, if they're going to disproportionately affect services in the community, that's going to raise Olmstead issues, and you're actually moving back on the ADA's integration mandate.

So, that's creative lawyering. We'll see how effective it's going to be, again because some of our federal judges are not that friendly to the ADA. But I feel like we're going to have more luck on that front.

There's also an interest in Washington in passing another round of stimulus money after healthcare reform is over. So it's possible in the first quarter of next year you all could explain one of the things that there's a need for is more stimulus money to help shore up Medicaid programs that are struggling.

The other buried issue in healthcare reform that I'll just mention is healthcare reform. The bill that passed the House

has an expansion of Medicaid. And we sent a letter up to the House expressing a concern that as we expand Medicaid, that can create even more pressure on Medicaid budgets. And the stuff that people with disabilities need to live in the community is typically optional. So if they're required to serve more people, they're going to look for ways to cut, they may try to cut the optional services. So we're trying to get some kind of maintenance of effort requirement in there so that they can't take this expansion and use it as an excuse to shrink what's available for optional services in the community.

But, again, I really encourage you to talk to your House member and your Senators exactly about this issue because it is something they need to hear about from the ground.

Hand up in yellow sweater.

>> Two questions for you. One question is: I'm putting in for the age and disabled waiver. And one point that you made that comes into mind when it comes down to the age and disabled waiver, you mentioned about how people are looking at disabilities that are visible and about some disabilities that aren't visible, how people are not seeing the disabilities that aren't all that visible.

Well, when I'm putting in for the age and disabled waiver, I have a hard time with trying to get approved for the age and

disabled waiver because my disability with having seizures and some other issues regarding psychiatric level are not all that visible. And it's hard to get completely approved because that's not all that visible. And getting approved is not all that easy for the AD waiver. So it's kind of a catch-22. But I'm slowly close to getting approved right now.

And then the other question that I have is on the healthcare bill, if we don't get the public option without it, would that prevent people with Medicare/Medicaid being prevented from going to private hospitals?

>> ANDREW IMPARATO: There's two questions. The second question relates to healthcare reform. And the question says if we don't get a public option, is that going to have an impact where people on Medicaid or Medicare would not be able to go to private hospitals?

You got a whole panel that's going to do healthcare reform tomorrow, so I'm going to let them answer it. I'm not aware of any reason why healthcare reform without a public option would make it harder than it is right now for people on Medicaid or Medicare to go to a private hospital, but I'll let your experts tomorrow get into the more detail on that.

In terms of your first question about your own personal becoming eligible to get services under a particular waiver,

most waivers are going to define services based on your functional needs as opposed to your diagnosis. And you said you're making progress there. I think the more medical evidence you can put forward that documents the functional impact of your disability, the more you're going to be able to show that you have the same needs that the target population has for that waiver.

The one thing I'll say is it helps to have a lawyer when you're having these kind of fights around eligibility. Most people don't see it as a legal issue. But if you can get a Legal Services attorney or somebody from the Protection and Advocacy agency to help, they know kind of the different ways -- and oftentimes it also helps to appeal. And if you keep appealing denials and you're persistent, it's a lot easier to prevail than to do it on the first try. But we can talk more offline. But that's just some quick advice on that.

Yeah, in the green shirt.

>> In terms of genetic information, can you explain more about what you meant by that?

>> ANDREW IMPARATO: So you're going back to a term and explain more about genetic information? Genetic. Yeah. Thank you for that question. This is actually an issue that doesn't get enough attention sometimes in the disability community.

But we had a federal law that took about 15 years to pass that passed in the last Congress called the Genetic Information Nondiscrimination Act that prohibits employers and healthcare insurers from discriminating on the basis of genetic information.

So if they find out that you have a genetic predisposition for a certain condition, they can't not hire you or not insure you based upon your genetic predisposition. The Department of Labor is in the process of writing rules on that.

But here's the bigger picture issue around this. We've invested a lot of federal money in the Human Genome Project, and we're going to have a lot more information available to us prenatally than we've ever had historically. So parents are going to get a lot of information about what are the chances that their kid might develop any number of conditions. And I don't feel like we're ready for that as a society.

And so one of the things that is in our 12-point plan that we're working on with our Justice Action Network is we're calling for a Congressional taskforce to look at human genetic technologies and disability rights and really try to make sure that we're not going to have a new round of eugenics where we're trying to eliminate people with disabilities prenatally or we're using genetic information in a way that discriminates against

people with disabilities after they're born.

And I think as you're talking about 20 years of ADA, I think all of this genetic stuff is going to become more and more important in the future as there's more and more information.

>> One more question if I may -- [inaudible] Human Rights Commission and as you spoke about protective classes of people now, would that include people that are HIV positive?

>> ANDREW IMPARATO: Okay. So the last question, the gentleman said on his city's Human Rights Commission, and you're asking whether the ADA Amendments Act or the genetic bill would exclude people that are HIV positive?

>> Or include.

>> ANDREW IMPARATO: People who are HIV positive but asymptomatic were found by the Supreme Court to be covered by the ADA, one of their good decisions, called Bragden versus Abbott. So they weren't exactly a target of the ADA Amendments Act, but the analysis in the ADA Amendments Act is going to make it even easier for people who are HIV positive to come under the ADA.

>> All right, thank you.

>> ANDREW IMPARATO: So I think do we have time for more or should we wrap it up? A couple more. Okay. So the person in the maroon shirt and the white cane.

>> I first of all want to thank you for mentioning the situation here in the state of Indiana with the absentee voting.

My question specifically, since I'm the gentleman that's dealing with this, is what your thoughts on where I should take it next. Because I did get a decision, as you mentioned, from the state of Indiana, and the state of Indiana dismissed it. But I have myself appealed it because the state told me that I could not appeal it because since the state of Indiana did not do an investigation, under Title 3 of Pava, the state of Indiana is hiding behind the words "polling places" and polling places only refers to election day.

>> ANDREW IMPARATO: Yeah, as I said earlier, I think voting is changing, and it's a good thing. We're trying to make it easier for people to vote. We're trying to eliminate the long lines on election day. So those changes need to be implemented in a way that people with disabilities have equal access.

I think the best person to raise that with is Sam Bagenstos, who is the Deputy Assistant Attorney General for Civil Rights. And his email is Samuel.bagenstos@USDOD.gov. I would raise it with him. And let's talk more offline. I'm sure you know Jim Dixon on my staff. But we'd like to support you on that effort.

Again, to me, this is going to be more and more important

because more and more states are doing this. So we want to make sure they're doing it right.

>> Thank you.

>> ANDREW IMPARATO: Yeah.

>> Could you clarify the status of the progress of the transition to economic sufficiency proposal that you referred to?

>> ANDREW IMPARATO: So the question is I mentioned a proposal that came out of our bipartisan Ticket to Work panel of a new program called Transition to Economic Self-Sufficiency. Right now it's an idea.

What we're trying to do is get the new leadership in the Obama Administration to recognize that there's an opportunity to lead here, that this is a big picture thing that would require a bipartisan approach. But it's consistent with the President's overarching desire to make the entitlement programs work better. So we're in the process of trying to get the idea out there.

And, again, I'm talking about it a lot when I travel around the country because I want some states to start showing the national government how to do this. And if you have the right leadership at the state level, between the VR agency, the Medicaid agency, the Governor, whatever, there's an opportunity to get the Feds to waive whatever requirements they have to do

that.

Social Security has a demonstration authority in their statute where they can fund demonstrations at the state level to demonstrate new ways to do programs.

So, again, I think this is the kind of thing where we need to raise it nationally, but we also need to raise it at the state and local level and let people demonstrate how to do it.

>> Cut my Medicare down. They are going to cut it down.

>> ANDREW IMPARATO: You're talking about the cuts on Medicaid at the state level? Again, my message to you is grow a list of people who agree with you so that instead of it just being you saying "don't cut my Medicaid," you've got a list.

Just to give you an example, in Tennessee, the Tennessee Disability Coalition has a list of 140,000 voters in Tennessee that they communicate with around elections.

If you don't want to be vulnerable to those kinds of cuts, then we have to be better organizers in the community to push back. And getting organized is about growing lists. And there's ways to do that with technology. But there's also ways to do it just working through the organizations that are represented here at this Conference.

But you're right. They shouldn't cut your Medicaid. It's going to have a Draconian impact on people on the ground. I

encourage you to deliver that message to the people who are making those decisions to the state legislature and to the Governor's office.

Let's just do one more.

>> Jody: You said a new health era. What is it?

>> ANDREW IMPARATO: You said there was a new mental health bill, what is it? Again, this is a bill that was percolating in Congress for many years and it finally passed in the last Congress. It's called the Mental Health Parity legislation. And it basically says that health insurers cannot discriminate between physical health and mental health and provide lots of services with no caps on the physical health side but have a lot of arbitrary caps on the mental health side. So it's going to make it easier for people who need mental health treatment to get the treatment on a par with the kind of treatment they would get if they needed treatment for a physical problem.

>> When does it take effect? Psychiatric nurse here at a local hospital. That's nice that they passed it, but when is it going to start happening?

>> ANDREW IMPARATO: Well, the bill passed in the last Congress. I think the effective date was projected out a couple of years because there needed time to write the regulations and work out the details. But, unfortunately, I don't remember when

the effective date is. But the bill is passed. So it's now they're in the process of writing the regulations.

Do you guys know, on any chance, the effective date? I'll try to find it. If you give me your card, I will get it to you.

Anyway, thank you all very much. It's been great being with you.

[Applause.]

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